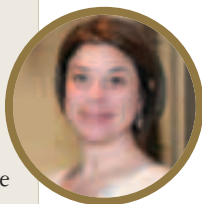
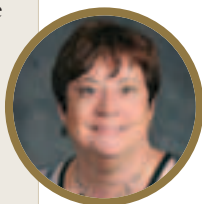


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## REACHING OUT TO FAMILIES OF DEAF AND HARD OF HEARING CHILDREN IN ILLINOIS:

# a collaborative effort

*By Karen Aguilar, Marcia Breese, Gail Olson, Cheri Sinnott, and Michele Westmaas*

In Illinois, several organizations collaborate to provide a comprehensive approach to family outreach for families of students who are deaf and hard of hearing. Some of the agencies that work together in this effort are CHOICES for Parents, Illinois Hands and Voices, Guide By Your Side, Illinois Service Resource Center, Illinois School for the Deaf Outreach, and Hearing and Vision Connections. This network of support provides such services and resources as parent-to-parent networking, in-home individual support, training, parent groups, and conferences.

**CHOICES for Parents** is a statewide coalition of parents and professionals that provides parents of children who are deaf or hard of hearing with support, resources, information, and advocacy. CHOICES for Parents provides one-on-one parent support as well as activities throughout the year for parents and families.

Through collaboration with the Illinois Deaf Latino Association, outreach and support to Latino families is provided. A Deaf Awareness Day event and parent workshops occur annually, and sign language classes are taught in Spanish to parents who primarily speak Spanish.

The CHOICES for Parents READ Program ensures that children with hearing loss and their schools have books available to them. Through collaboration with the American Library Association, Hall-Erickson and GES Exposition Services, CHOICES for Parents distributes books throughout the state to programs and schools with deaf and hard of hearing children to promote early literacy.

*Children and Hearing Loss* is a free resource manual that is filled with information about hearing loss, early intervention, technology, education, pediatricians, and more. Produced by CHOICES for Parents, the resource is available in English and Spanish.

Every spring on Early Hearing Detection & Intervention (EHDI) Day, CHOICES for Parents honors those who have gone above and beyond in infant identification and follow-up. CHOICES for Parents works with the Illinois Governor's Office to proclaim EHDI Day annually in the state. During the event, parents are invited to share their stories on receiving the news of their children's hearing loss and the support that they received.

*Photos courtesy of Carrie Balian*



As a result of CHOICES for Parents' collaboration with Illinois Hands & Voices and the Illinois EHDI program, the Illinois Guide By Your Side Program was implemented in 2009. Illinois Hands & Voices is a parent-driven organization dedicated to supporting families who have children who are deaf and hard of hearing without a bias toward communication modes or methodologies. Illinois families receive support in order to improve communication access and educational outcomes for their children through workshops, parent gatherings, and the national newsletter, *Hands & Voices Communicator*.

The Illinois EHDI program works to implement mandated newborn hearing screening no later than 1 month of age, diagnosis no later than 3 months of age, and intervention no later than 6 months of age. The EHDI program encompasses outreach and support to parents, hospitals, family physicians, state agencies, and providers regarding the diagnosis and follow-up of children with hearing loss. The Illinois EHDI program state partners are the University of Illinois at Chicago Division of

Specialized Care for Children, the Illinois Department of Public Health, and the Illinois Department of Human Services. In addition, the program collaborates with numerous groups to increase newborn hearing follow-up, diagnosis, intervention, parent support, and continued surveillance of hearing prior to entering school.

**Guide By Your Side** provides unbiased emotional support and resources by trained parent guides to families with children who have a hearing loss. Parent guides are parents whose children have hearing loss with varying modes of communication and educational paths chosen. Parent guides represent different cultures and ethnicities; are deaf, hard of hearing, or hearing; and are, in many cases, bilingual. In Illinois, this fills a much needed gap of individual parent-to-parent support.

What do parents have to say about Guide By Your Side? One parent commented, "I'm learning sign language to communicate with my son and I wondered if there were other parents out there who wanted to learn, too. My parent guide encouraged me

**Above left:** During Guide By Your Side's Family Fun Day event, families participated in games, face painting, and other fun activities.

**Above right:** During a family social event for children with hearing loss, children had the opportunity to meet Monkey Joe.

*to reach out to other parents and explained ways that I could network with them. I started a deaf coffee chat in my town for people to come together to learn sign language and it's been a great way to meet other parents who have deaf or hard of hearing kids!"*

Another parent said, "*The Guide By Your Side mentor program has helped me tremendously! My relationship with my mentor started when I was literally in a 'survival mode' dealing with the news of my son's hearing loss. Over a period of six months, my mentor has taken the time out to speak to me about everything that was on my mind. We talked about how to recognize personal emotions, deal with close friends who have not experienced a similar life-changing event and hence cannot connect on the same level, build a stronger relationship with the spouse and allow one another the time to accept the new challenge in our life. As time progressed, our*

*conversations also took on a new life. We talked about schooling options, various auditory therapy methods widely used and the benefits and flaws of each, American Sign Language and other resources that are available to the parents. My mentor sends me regular updates on upcoming national or state events on hearing loss and we have even talked about the cultural dimension around hearing loss and helpful ways to deal with it. I feel I have a friend I can talk to any time; someone who gives me a very unbiased view about everything."*

**The Illinois Service Resource Center (ISRC)** is a component of the Illinois State Board of Education's Illinois Statewide Technical Assistance Center. ISRC provides behavior support for schools and families of students who are deaf and hard of hearing. Meaningful parent involvement in a child's education can be an important factor in student behavior.

In an effort to address the issue of increasing meaningful parent involvement, ISRC has hired five regional parent facilitators. The parent facilitators can assist with locating speakers for parent groups, help connect parents with resources such as service providers and educational programs, help parents learn about Deaf culture, and facilitate connections between home and school and parent to parent.

Parent facilitators also coordinate a Parent Café, at which parents have the opportunity to come together while their children are provided with an activity. The Parent Cafés take place on the same date in all five regions of the state.

Another resource for parent-to-parent support is the ISRC Family Network. ISRC maintains a directory of parents and families with children who are deaf and hard of hearing. ISRC parent facilitators are able to connect parents with other parents facing similar circumstances, such as parents of children who are "deaf plus," meaning



**Meaningful parent involvement in a child's education can be an important factor in student behavior.**

that in addition to being deaf the children also have a secondary challenge such as autism, Down syndrome, learning disabilities, vision impairment, or behavior challenges. One Family Network member said, *"Some of these children are so unique, it is rare to find another parent with a similar experience."*

The ISRC Resource Library includes over 75 items specifically tailored to parent/family needs. This is in addition to over 1,000 other items with a focus on deafness and behavioral issues. Families may request items via phone, e-mail, or fax, and the items are mailed to the

families with return postage included.

While providing behavior support to schools, ISRC assists with the development of Positive Behavior Interventions and Supports (PBIS) for deaf and hard of hearing programs. Parent involvement is a significant aspect of PBIS, and ISRC encourages programs to have a parent member on the PBIS Leadership Team, to incorporate home-school activities and behavior incentives, and to invite families to PBIS annual kickoff events.

Individual support for families of students who are experiencing behavior challenges at home is provided by ISRC. A member of the team visits the family and assists in the development of a Home-School Team. This team identifies behavior support strategies that can be consistent at both school and home.

The ISRC website ([www.isrc.us](http://www.isrc.us)) includes a page specifically for parents. The page includes contact information for the parent facilitators and helpful information such as tip sheets for summer survival, potty training, basic sign language, and sample behavior charts.

Each year ISRC sponsors a bus trip for families that would like to visit the Illinois School for the Deaf (ISD). Families who are considering sending their child to the school but have never had an opportunity to visit are able to participate in this one-day free bus trip and experience a day at the residential school.

**Illinois School for the Deaf (ISD) Outreach** is the statewide resource center which supports the education of students who are deaf or hard of hearing from birth to age 21. Utilizing the wealth of knowledge and experience related to hearing loss and related issues available at ISD, ISD Outreach offers consultation and technical assistance free of charge to teachers, parents, support staff, and



other service providers who work with children who are deaf or hard of hearing.

ISD Outreach services are free. Parents often request in-service presentations for educators in general education classrooms as well as observations, phone or e-mail consultations, and written correspondence. Free trainings are provided upon request to parent groups on a variety of topics related to hearing loss.

Parents have fewer opportunities for summer activities for their children with hearing loss, and that can cause stress. ISD Outreach offers summer camp opportunities for students with hearing loss, an open house, "Taste of ISD" for parents of ISD students, and collaborates on parent conferences held throughout



PHOTO BY CATHERINE VALCOURT-PEARCE

the state. Another resource for parents of children newly diagnosed with hearing loss is a one-week institute for parents of preschool children.

Free assessments to identify educational and vocational needs are provided by the ISD Evaluation Center. Evaluations and assessments are available in the areas of school psychology, audiology, and communication skills. Vocational evaluations that identify career interests

and abilities are available to high school students. Evaluations are free; however, the family or referring school is responsible for transportation, meals, and lodging, if needed.

ISD Outreach offers a new Cochlear Implant Program to support the education of students with cochlear implants by providing training and technical assistance specific to cochlear implants. These services are provided by a person who is a late deafened adult and cochlear implant user. General cochlear implant information is also available on the ISD Outreach website.

In addition to the services offered to parents, ISD provides a variety of services for educators and other professionals. For information about the full range of services offered by ISD Outreach, visit the website at [http://morgan.k12.il.us/isd/outreach\\_services.html](http://morgan.k12.il.us/isd/outreach_services.html).

### Hearing and Vision

**Connections** (HVC) is a statewide training and technical assistance program serving infants and toddlers who are deaf, hard of hearing, or visually impaired. HVC is funded by the Illinois Department of Human Services, Bureau of Early Intervention.

HVC offers:

- Free training opportunities throughout the state for early intervention service providers and collaborates to provide annual conferences for parents of children with hearing and vision loss. Parent conferences are held in the northern, central, and southern parts of the state.
- Resource and referral services to help early intervention service coordinators find vision and hearing specialists to serve the children on their caseloads. In addition, HVC answers families' and providers' questions specific to hearing and vision in infant/toddler development or service delivery.
- Many free resources to parents and providers. Resource guides are available for parents of young children

with hearing loss, vision loss, and dual sensory impairment. Free quarterly newsletters offer current information related to hearing and vision loss in young children.

- Networking opportunities for developmental therapists hearing and developmental therapists vision, early intervention providers specially trained to meet the needs of young children with hearing or vision loss, and deaf mentors, trained adults with hearing loss who provide support and information for families of young children with hearing loss. HVC also provides support for the credentialing of service providers in order to ensure adequate providers are available to meet the needs of children throughout the state.

The HVC website ([www.morgan.k12.il.us/isd/bvc](http://www.morgan.k12.il.us/isd/bvc)) offers newsletters, resource guides, and a training calendar as well as vision and hearing screening tools and early intervention service guidelines related to hearing and vision impairment. HVC works closely with the Bureau of Early Intervention to create and maintain the screening tools and service guidelines ensuring that young children with hearing or vision loss are identified and receive appropriate early intervention services as soon as possible.

There are many organizations in Illinois supporting parents on their journey of raising a child with hearing loss. However, instead of this being seen as a confusing overlap, all of these organizations are strong supporters of each other, working collaboratively for the benefit of the child and family needing support.

When hearing parents find out that their child is deaf or hard of hearing, the support of professionals and other parents is critical in navigating this new path. By reaching out to these parents, and to parents who themselves are deaf or hard of hearing, these agencies in Illinois provide not only a network, but a safety net for families.